

DOCUMENT RESUME

ED 353 712

EC 301 743

TITLE Spina Bifida: General Information. Fact Sheet Number 12 = La Espina Bifida: Informacion General. Fact Sheet Number 21.

INSTITUTION Interstate Research Associates, McLean, VA.; National Information Center for Children and Youth with Disabilities, Washington, DC.

SPONS AGENCY Special Education Programs (ED/OSERS), Washington, DC.

PUB DATE 92

CONTRACT H030A00002

NOTE 5p.

PUB TYPE Information Analyses (070) -- Multilingual/Bilingual Materials (171)

LANGUAGE English; Spanish

EDRS PRICE MF01/PC01 Plus Postage.

DESCRIPTORS Definitions; Early Intervention; *Educational Needs; Elementary Secondary Education; Health Services; Incidence; Learning Problems; Mainstreaming; Preschool Education; Pupil Personnel Services; School Health Services; *Special Health Problems; *Spina Bifida; Student Characteristics; *Symptoms (Individual Disorders)

ABSTRACT

This fact sheet on spina bifida is offered in both English and Spanish. It provides definitions of the three types of spina bifida (spina bifida occulta, meningocele, and myelomeningocele). Incidence figures are given as are typical characteristics of children with spina bifida. Educational implications are briefly noted, including the need to accommodate these children's frequent need for surgery; provision of clean, intermittent catheterization as a related service; early intervention with hydrocephalus-related learning problems; adaptations in equipment or curriculum to maximize mainstreaming; and special instruction in mobility skills. The fact sheet lists two print resources and five organizations. (DB)

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General Information About SPINA BIFIDA

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◆ Definition ◆

Spina Bifida means cleft spine, which is an incomplete closure in the spinal column. In general, the three types of spina bifida (from mild to severe) are:

1. **Spina Bifida Occulta:** There is an opening in one or more of the vertebrae (bones) of the spinal column without apparent damage to the spinal cord.
2. **Meningocele:** The meninges, or protective covering around the spinal cord, has pushed out through the opening in the vertebrae in a sac called the "meningocele." However, the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.
3. **Myelomeningocele:** This is the most severe form of spina bifida, in which a portion of the spinal cord itself protrudes through the back. In some cases, sacs are covered with skin; in others, tissue and nerves are exposed. Generally, people use the terms "spina bifida" and "myelomeningocele" interchangeably.

◆ Incidence ◆

Approximately 40% of all Americans may have spina bifida occulta, but because they experience little or no symptoms, very few of them ever know that they have it. The other two types of spina bifida, meningocele and myelomeningocele, are known collectively as "spina bifida manifesta," and occur in approximately one out of every thousand births. Of these infants born with "spina bifida manifesta," about 4% have the meningocele form, while about 96% have myelomeningocele form.

◆ Characteristics ◆

The effects of myelomeningocele, the most serious form of spina bifida, may include muscle weakness or paralysis below the area of the spine where the incomplete closure (or cleft) occurs, loss of sensation below the cleft, and loss of bowel and bladder control. In addition, fluid may build up and cause an accumulation of fluid in the brain (a condition known as hydrocephalus). A large percentage (70%-90%) of children born with myelomeningocele have hydrocephalus. Hydrocephalus is controlled by a surgical procedure called "shunting," which relieves the fluid buildup in the brain. Hydrocephalus may occur without spina bifida, but the two conditions often occur together. If a drain (shunt) is not implanted, the pressure buildup can cause brain damage, seizures or blindness.

◆ Educational Implications ◆

Although spina bifida is relatively common, until recently most children born with a myelomeningocele died shortly after birth. Now that surgery to drain spinal fluid and protect children against hydrocephalus can be performed in the first 48 hours of life, children with myelomeningocele are much more likely to live. Quite often, however, they must have a series of operations throughout their childhood. School programs should be flexible to accommodate these special needs.

Many children with myelomeningocele need training to learn to manage their bowel and bladder functions. Some require catheterization, or the insertion of a tube to permit passage of urine.

The courts have held that clean, intermittent catheterization is necessary to help the child benefit from and have access to special education and related services. Many children learn to catheterize themselves at a very early age.

A successful bladder management program can be incorporated into the regular school day.

In some cases, children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school.

Mainstreaming, or successful integration of a child with spina bifida into a school attended by nondisabled young people, sometimes requires changes in school equipment or the curriculum. Although student placement should be in the least restrictive environment the day-to-day school pattern also should be as "normal" as possible. In adapting the school setting for the child with spina bifida, architectural factors should be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds make their facilities accessible. This can occur through structural changes (for example, adding elevators or ramps) or through schedule or location changes (for example, offering a course on the ground floor).

Children with myelomeningocele need to learn mobility skills, and often require the aid of crutches, braces, or wheelchairs. It is important that all members of the school team and the parents understand the child's physical capabilities and limitations. Physical disabilities like spina bifida can have profound effects on a child's emotional and social development. To promote personal growth, families and teachers should encourage children, within the limits of safety and health, to be independent and to participate in activities with their nondisabled classmates.

◆ Resources ◆

National Institute of Neurological and Communicative Disorders and Stroke. 1986. *Spina Bifida: Hope Through Research*. (Available from the Spina Bifida Association of America. See address under organizations.)

G. (Ed.) *Children with Spina Bifida: Early Intervention and Preschool Programming*. 1987. (Paul H. Brookes Publishing Co., Baltimore, MD)

◆ Organizations ◆

Spina Bifida Association of America
4590 MacArthur Boulevard, Suite 250
Washington, D.C. 20007
(202) 944-3285
(1-800) 621-3141 (Toll Free)

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

National Center for Education in Maternal and Child Health
38th and R Streets, N.W.
Washington, D.C. 20057
(202) 625-8400

National Easter Seal Society
70 E. Lake Street
Chicago, IL 60601
(312) 726-6200
(1-800) 221-6827 (Toll Free)

National Rehabilitation Information Center (NARIC)
8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319
(301) 588-9284
(1-800) 346-2742 (Toll Free)

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UPDATE 3/90

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Información General Sobre LA ESPINA BIFIDA

♦ Definición ♦

Espina Bifida quiere decir una partidura en la espina, o sea que la columna vertebral no se ha cerrado completamente. Hay tres tipos de espina bifida (varían de leve a severo) y éstos son:

1. **Espina Bifida Oculta:** Una apertura en una o más de las vértebras (huesos) de la columna espinal, sin ningún daño aparente a la médula espinal.
2. **Meningocele:** Los meninges (o cobertura protectora que rodea la médula espinal) se han salido a través de una apertura en las vertebras, en un saco llamado el "meningocele."
3. **Myelomeningocele:** Esta es la forma más severa de espina bifida, en la cual una porción de la médula espinal sobresale a través de la espalda. En algunos casos, los sacos están cubiertos de cutis; en otros, los tejidos y nervios están expuestos. Generalmente, los términos "espina bifida" y "myelomeningocele" son usados en forma intercambiable.

♦ Incidencia ♦

En los Estados Unidos, aproximadamente el 40% de la población puede tener espina bifida oculta, aunque muy pocas de estas personas lo llegan a saber ya que esta condición carece de síntomas. Los otros dos tipos de espina bifida, meningocele y myelomeningocele, son conocidos como "espina bifida manifiesta," y esto ocurre en aproximadamente uno de cada 1,000 infantes. De los infantes que nacen con "espina bifida manifiesta," más o menos el 4% tiene meningocele y el 96% tiene myelomeningocele.

♦ Características ♦

Los efectos de myelomeningocele, la forma más grave de la espina bifida, pueden incluir debilidad

muscular o parálisis bajo el área donde ocurre la apertura (o hendidura), falta de sensación bajo la hendidura, e incontinencia. Existe el peligro, además, de una acumulación anormal de líquidos en el cuerpo y por lo tanto en el cerebro (lo que resulta en una condición llamada hidrocefalia). Un gran porcentaje (70%-90%) de los niños que nacen con myelomeningocele tienen hidrocefalia. La hidrocefalia se controla mediante una intervención quirúrgica llamada procedimiento de derivación (shunt). Este procedimiento consiste en la introducción de una punta de un tubo flexible en un ventrículo cerebral, sacando el tubo por una pequeña apertura en el cráneo. La hidrocefalia puede ocurrir sin la espina bifida, aunque frecuentemente se manifiestan juntas ambas condiciones. Sin la derivación (shunt) puede resultar una acumulación de líquidos en el cerebro, y esta presión puede causar daño cerebral, ataques, o ceguera.

♦ Implicaciones en la Educación ♦

Los estudiantes con espina bifida son elegibles para recibir servicios de educación especial bajo el Acta para la Educación de las Personas con Discapacidades (Ley Pública 94-142). La espina bifida se clasifica como "impedimento a la salud" (other health impaired) y la escuela y los padres tienen que desarrollar un Plan de Educación Individual (IEP) a fin de especificar los servicios apropiados.

Aunque la espina bifida es relativamente común, hasta hace poco la mayoría de los niños que nacían con myelomeningocele morían poco después de nacer. Ahora que el procedimiento de derivación para drenaje de líquido espinal puede llevarse a cabo durante las primeras 48 horas de vida, existen mayores posibilidades de que los niños con myelomeningocele puedan sobrevivir. En muchos casos, estos niños deben ser sometidos a una serie de operaciones a través de su niñez. Los programas escolares deben ser flexibles para acomodar estas necesidades especiales.

Muchos niños con myelomeningocele necesitan entrenamiento para el control de la incontinencia. Algunos requieren un catéter, o un tubo de hule o de metal que se introduce por el extremo inferior de la uretra a la vejiga, para permitir que la orina fluya libremente por el tubo y el chorro de la orina puede dirigirse a un recipiente.

El cateterismo, limpio e intermitente, es necesario para ayudar al niño a beneficiarse de y para tener acceso a la educación especial y servicios relacionados. Por lo tanto, de acuerdo a las cortes, la escuela debe proveer el cateterismo como servicio relacionado a todos los niños que lo requieren. Además, muchos niños aprenden a usar el catéter a una edad temprana.

En algunos casos, los niños con espina bífida que también tienen hidrocefalia experimentan trastornos del aprendizaje. Pueden tener dificultades con poner atención en la clase, en la comprensión o expresión, en leer, y en aritmética. Para los niños con trastornos del aprendizaje la intervención temprana les puede ayudar a prepararse para ir a la escuela.

La integración de un niño con espina bífida a la escuela con niños que no tienen discapacidades a veces requiere cambios en el ambiente colegial o al currículo. Aunque el estudiante debe colocarse en un ambiente con un mínimo de restricciones, el horario colegial también debe ser lo más normal posible. Varios factores arquitectónicos deben ser considerados antes de la adaptación del ambiente escolar. Hay que recordar que la Sección 504 del Acta de Rehabilitación de 1973 requiere que los programas que reciben fondos federales tengan accesibilidad para los niños con discapacidades. Esto puede incluir cambios estructurales (como, por ejemplo, agregar ascensores o rampas para sillas de ruedas) o mediante cambios de horario o ubicación de la sala de clases (por ejemplo, ofrecer la clase en el primer piso).

Los niños con myelomeningocele necesitan aprender destrezas de movilidad, y frecuentemente requieren el uso de muletas, aparatos ortopédicos, o sillas de rueda. Es importante que tanto los miembros del equipo escolar como los padres comprendan las capacidades físicas del niño y sus limitaciones. Las discapacidades físicas como la espina bífida pueden tener un profundo efecto en el desarrollo socio-emocional del niño. Para promover el crecimiento

personal las familias y los profesores deben alentar a los niños, dentro de los límites de la salud y bienestar, para que éstos puedan ser independientes y participar en las mismas actividades que sus compañeros sin discapacidades.

♦ Recursos ♦

Spina Bífida Association of America. 1984. El Niño con Espina Bífida. Washington, DC: Spina Bífida Association of America. (Teléfono: (800) 621-3141.)

National Institute of Neurological and Communicative Disorders and Stroke. 1986. Spina Bífida: Hope Through Research. (Ponerse en contacto con: Spina Bífida Association of America. Teléfono: (800) 621-3141.)

♦ Organizaciones ♦

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UPDATE10/92